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Using experience-based design to understand the patient and caregiver experience with delirium

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Abstract

Hospital-acquired delirium negatively affects clinical outcomes and the care experience for patients and family caregivers. Following the qualitative methods of experience-based design, we completed observations of hospital units and interviews of patients, caregivers (including family members and other companions), and hospital nurses and other staff regarding their experiences with delirium. In addition, we administered an experience-based design questionnaire to another 130 subjects from the same groups. Key findings included: there is a need for preparation of the patients and family caregivers for the possibility of delirium (particularly before surgery), and patients and caregivers lack understanding of delirium and its potential prolonged aftereffects. We identified that caregivers may both contribute and detract from delirium care as they: (1) often identify delirium early; (2) are invaluable for supporting patients during re-orientation after delirium episodes; (3) frequently lack the preparation and skills for adequate delirium detection and response; (4) may not be present at critical times; (5) can be challenging for the delirium management team, and (6) are frequently discussed as the person who best understands the patients' baseline cognitive state and behavior. Experience-based design is an innovative framework to increase our qualitative understanding of the patient and caregiver experience during and following episodes of hospital acquired delirium.

Keywords

Patient experience, delirium, experience-based design, experience-based co-design, caregiver roles

Introduction

Delirium is defined as acute cognitive impairment and confusion, affects 29-64% of hospitalized patients, and is common in older adults.¹ Delirium is associated with an increased risk of death, increased hospital length of stay, morbidity, decreased function, patient aggression and violence, and increased staff injuries.²⁻⁸ Delirium is difficult to recognize, and often poorly diagnosed by hospital staff.⁹ The symptoms of delirium may fluctuate, contributing to delayed diagnosis and prolonged hospitalization, increasing risk of complications including cognitive and functional decline. However, delirium is potentially preventable, and may therefore be an important indicator of both patient safety and quality of health care delivery.¹⁰

Diagnosis of delirium requires identifying a change from the patient's cognitive baseline state. Accordingly, the potential role of caregivers (defined for this paper to be inclusive of both family members, and other friends or companions who provide voluntary support or care in the home for the patient), with their unique perspective on the

baseline cognitive state of the patient, is increasingly recognized.^{11, 12} However, research on the involvement of such caregivers for identification and treatment of delirium in hospitalized patients remains limited. Inouye and colleagues developed the Family Confusion Assessment Method (FAM-CAM) for use in interviewing family caregivers about the status of a patient to identify delirium.¹³ The Fam-HELP program was a multicomponent intervention that targeted activities that family caregivers could engage in to support patient re-orientation.¹⁴ In another study, participating family members implemented delirium interventions based on advice provided by hospital staff, but individualized to the unique needs of each patient.¹⁵ Other efforts to enhance caregiver involvement in delirium care have focused on education of caregivers.¹⁶

An important challenge with involvement of caregivers in delirium detection is the potential emotional burden that patient delirium can impose.¹⁷⁻¹⁹ Previous research has identified an increased emotional toll on all involved stakeholders related to the presence of delirium.^{20, 21} The

importance of understanding the patients' emotional experience is emphasized in other research that has shown incomplete awareness of how frightening delirium can be to patients.²² In addition, a recent literature review by Day and Higgins, stressed that the understanding of the experiences of caregivers during delirium remains limited.²³

In this project, we employed the experience-based design²⁴⁻²⁶ mixed-methods approach to advance understanding of the patient and caregiver experience with delirium. In addition, we demonstrate how experience-based design supported co-design of novel tools to aid patients and caregivers in identifying delirium and mitigating the consequences.

Materials and Methods

Our investigation occurred at a 336-bed tertiary care hospital in the Pacific Northwest, with 15,000 annual admissions. The institutional review board determined that the work was quality improvement and exempt from review.

Design

Using the experience-based design methodology,²⁴⁻²⁶ we employed a mixed-methods process of observations, interviews, and questionnaires to explore the experiences of patients with delirium and their caregivers (such as family members and other companions) from multiple perspectives within the hospital environment. Second, through a set of co-design sessions with key stakeholders, we developed tools and processes designed to enhance caregiver education about delirium and facilitate their involvement in detecting and responding to signs of delirium.

Experience-based design is based on the identification of "touch points," the periods of high emotional content that have strong influence on the overall care experience.²⁴⁻²⁵ These touch points are defined from interviews and focus groups. Experience-based design questionnaires can then be used to semi-quantitatively define the emotional content of each touch point by having subjects select one word from a predefined list of validated emotion words²⁶ that best corresponds to the emotional content of that touch point. Individual responses are combined to summarize the overall negative or positive experience of each touch point. These experience-based design questionnaires provide complementary information to more traditional surveys of patients' perceptions of their care. Co-design is informed by the qualitative and semi-quantitative findings from the EBD process and can be targeted to address touch points with negative emotional content.^{24, 25, 27}

Observations

We completed 16 hours of observations of hospital units with known high incidence of delirium, including critical care units and acute care hospital floors. We also conducted 10 patient and 4 family/caregiver interviews on the care experience. To provide an additional perspective on the patient and caregiver experience, we supplemented with interviews of 16 staff members on their perceptions of the patient and caregiver experience with delirium. Patients were recruited for interviews based on a convenience sample of patients with a delirium diagnosis and hospital admission during the previous 12 months. In addition, the primary caregiver (e.g., spouse, companion or other family member) of interested patient participants was invited to take part in the interviews. Additional recruitment was conducted through an established Patient-Family Partner Program. Staff were recruited for interviews through flyers and email outreach to nurses and physicians from units where delirium had been diagnosed within the hospital. The observations and semi-structured qualitative interviews were conducted by trained experience-based design practitioners, and were audio recorded and transcribed. Four members of the research team coded the transcribed interviews using an iterative process. We developed emergent themes using a grounded theory approach²⁸ through axial and open coding, affinity diagrams, and team evaluation of data saturation when interview themes no longer presented new theories.

Questionnaires

From the observation and interview themes we identified emotional touch points and developed EBD questionnaires (Appendix) for the caregiver and patient experience with delirium. Between October 2014 and February 2015, all patient households with known in-hospital delirium from the previous 12 months were sent the EBD questionnaire to assess the emotional content of the identified touch points. In addition, care satisfaction surveys were administered to the same groups to define their overall perception of the support they received from the health care team regarding the delirium episode. Responses were received from 31 patients and 38 caregivers. An anonymous EBD questionnaire was distributed to staff members who worked on inpatient units with higher incidence of delirium. The questionnaire was distributed initially by email, with follow-up paper surveys, notices in staff areas, and communication by nursing leadership, with 61 staff members responding. All patient, caregiver, and staff observations, interviews and surveys were voluntary.

Participatory Co-Design Sessions

We invited patients, caregivers (including family members and other companions), and staff to participate in two participatory co-design sessions with the aim of developing a set of prototype tools and processes to address challenges with episodes of delirium from the patient and caregiver perspective. Participatory design is a user-centered design approach that, in contrast to other design methodologies, asks users to influence the design process directly. The participatory design process typically includes three stages of design research: 1) initial exploration of work through analysis of users, tasks, and context; 2) discovery and definition processes through interactive design; and 3) prototyping. In each session, the results to date from the EBD observations, interviews, and questionnaires were shared with the group, who then engaged in several facilitated creativity activities (e.g. assumption busting, word play, idea generation and sorting). The sessions were conducted by a clinic nurse leader and the current head of our Patient Relations department. Participants were not compensated (though staff did participate during normal paid working hours).

Results

Patients who had undergone a delirium episode and who responded to the questionnaire tended to be older, with

88% (30/34) over the age of 60 years. The hospital stays with the delirium episode were most commonly 3 to 5 days in length (44%, 14/32), with 25% (8/32) 6 to 9 days and 22% (7/32) 10 or more days. Most included patients were Caucasian (91%, 31/34), with nearly equal numbers of male and female (male 53%, 17/32).

The observations and interviews revealed key touch points in the care process for patients who developed delirium, and their caregivers/family members. Patient touch points ranged from preparatory conversations with staff before the episode, through the delirium episode itself, to persistent memories of the delirium after resolution (Figure 1A). Not surprisingly, the emotional content of the delirium experience for patients was overwhelmingly negative. The only delirium touch point that was rated as more positive than negative was in regard to the staff's treatment approach. Touch points around delirium around delirium discussions before the episode and memories after the episode were more than 90 percent neutral/negative.

For caregivers, the key touch points ranged from the delirium episode itself, through communication around the episode, to the time of the patient returning home (Figure 1B). The emotional content of the delirium experience was also mostly negative. The only touch point that was

Figure 1A. Patients Delirium Experience Questionnaire Results

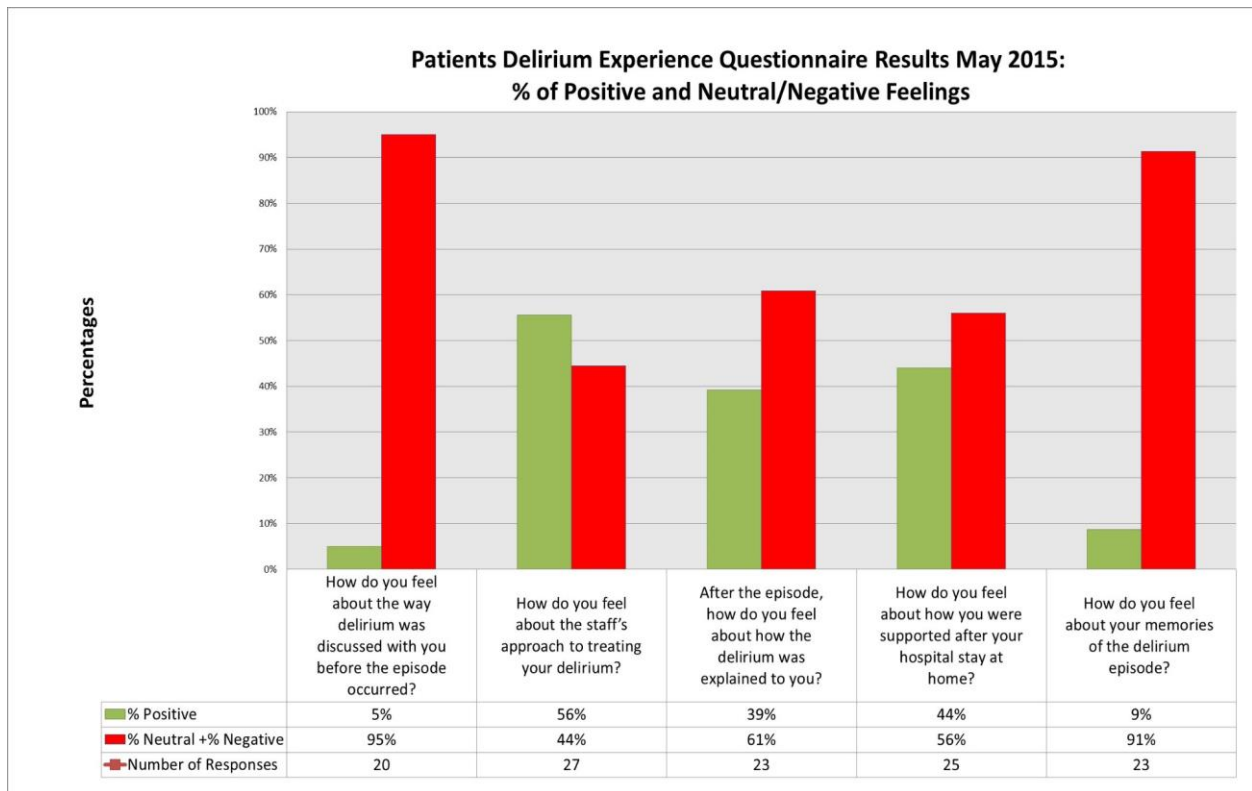
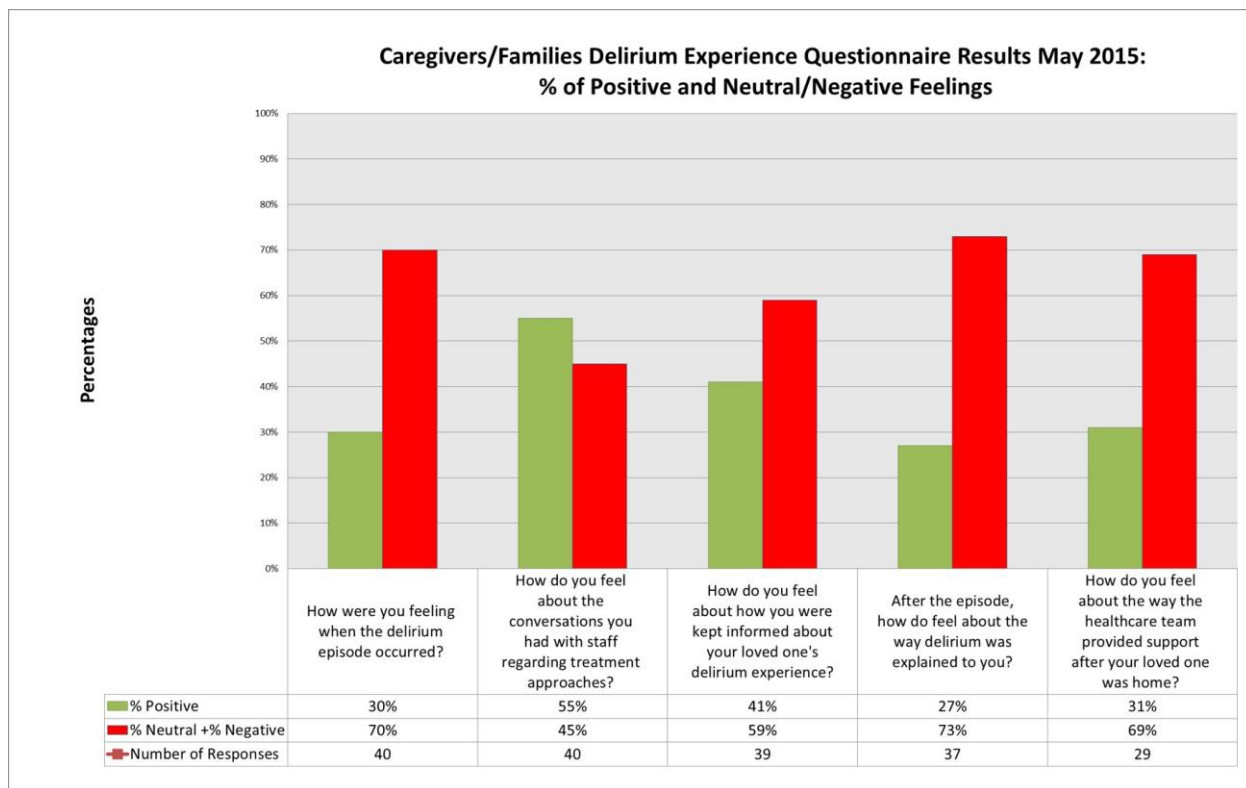


Figure 1B. Caregivers/Families Delirium Experience Questionnaire Results



rated as more positive than negative was how caregivers were kept informed about their loved one’s delirium experience. The most negative touch point for caregivers/families was returning home with the patient. Caregivers described being overwhelmed and underprepared for the care at home that was needed.

Staff also shared concerns regarding their own and patient’s care experience around delirium (Figure 1C). The most positive emotions were expressed when caregivers were available to discuss a delirious patient, and most negative when they were not. Staff also expressed concerns around communication with patients and family members, and on the level of involvement of caregivers in care.

Themes

Through triangulating voices from multiple stakeholders using the EBD mixed methods approach of observations, interviews and questionnaires, we identified a number of consistent themes related to delirium, both positive and negative. A series of assumptions were identified around the negative themes that were refuted through the EBD process, (summarized in Table 1, see Appendix). These refuted assumptions centered on preparation for the possibility of delirium (particularly before surgery), identification of delirium, understanding the delirium episode, and the lasting effects of delirium.

Preparation prior to surgery (feeling left in the dark)

Participants communicated varied responses pertaining to how they wanted to get information about delirium. Consistently, patients and caregivers felt underprepared regarding the risk and severity of delirium. This lack of knowledge may contribute to: (1) increased fear and confusion; (2) a potentially missed opportunity for caregivers to be involved in the early detection of the patient’s delirium; (3) a potentially negative relationship between the caregivers and hospital staff. However, participants differed in how much delirium preparation before surgery they considered to be an ideal amount.

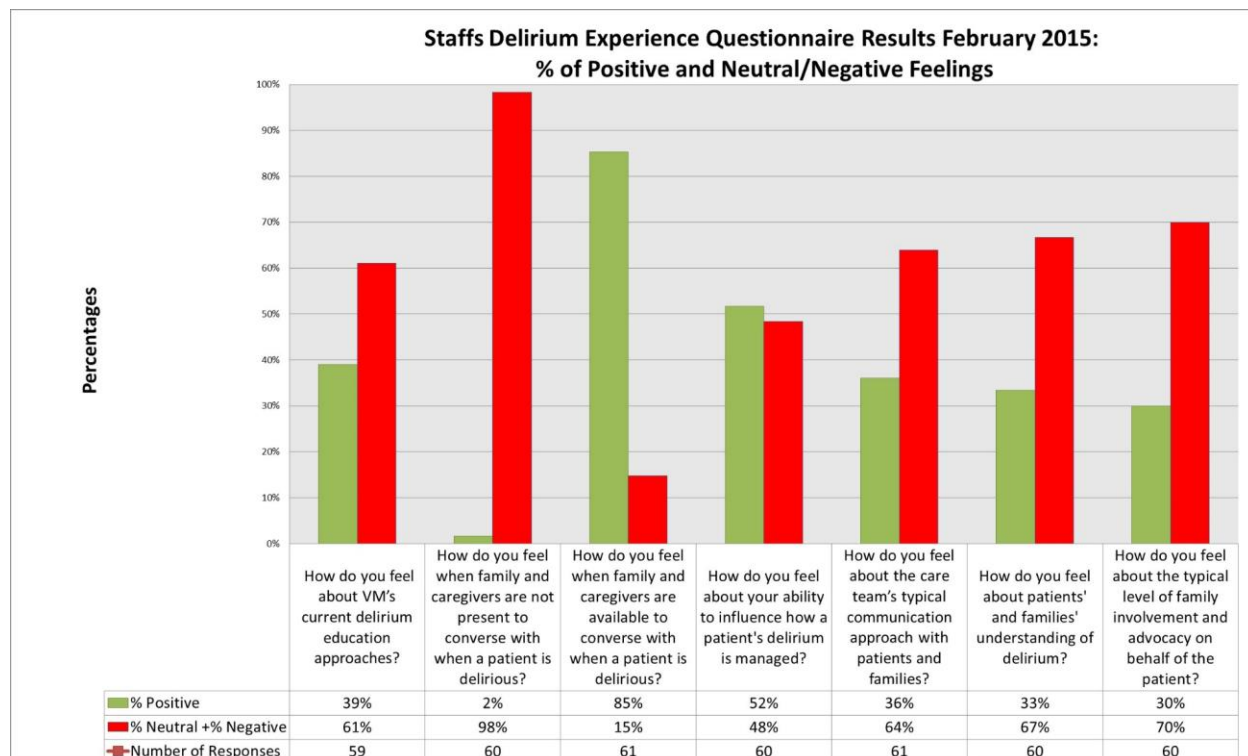
“Anything that you can do to counsel people ahead of time of what they’re going to be going through or give them an idea or say this might happen or this might happen or you may experience this...might help them bold onto some reality.”

“I kind of have mixed emotions about this preparing the patient philosophically, psychologically with a warning that this might happen.”

Identifying delirium

Patients and caregivers voiced awareness of changes in cognition before they were recognized by the medical team. Given the necessity to recognize change to diagnose delirium, the intimate knowledge of patients’ baseline state that caregivers afford can contribute to earlier diagnosis.

Figure 1C. Staff Delirium Experience Questionnaire Results



However, it may not be the spouse or even a family member who knows the patient best. Other caregivers, including friends, may have greatest awareness of the baseline state, and can be a resource for delirium diagnosis.

"[My son] told me later he went to the nurses' station and said, 'Something's wrong with him; he's not acting right.'"

Understanding delirium

Participants described feeling a lot of anxiety and distress relating to their experiences with delirium. Through the EBD questionnaire, participants described negative emotions of feeling angry, depressed, hopeless, disrespected and resentful relating to their experience with delirium. On the other hand, participants also used positive emotions to describe relationships with staff, including feeling grateful, joyful, and valued.

A common finding from participants was the perception that communication could be improved. When patients and caregivers were surveyed, "After the episode, how do you feel about the way delirium was explained to you?" 61% of patients (14/23) had a neutral/negative response; and 59% (23/39) of caregivers also had a neutral/negative response (Figures 1A and 1B). One caregiver wrote on her questionnaire that the delirium "was never actually explained to me." Similarly, when staff were asked, "How do you feel about the care team's typical communication

approach with patients and families", 64% (39/61) had a neutral/negative response (Figure 1C).

With regard to delirium education, both patients and staff conveyed this to be a touch point in need of development. An overwhelmingly 95% (19/20) of patients had a neutral/negative response to the question, "How do you feel about the way delirium was discussed with you before the episode occurred." Likewise, 61% of staff (14/23) had a neutral/negative response when asked, "How do you feel about [this hospital's] current delirium education approaches?" One nurse explained, "It feels like it is not discussed directly."

The lasting impact of a delirium experience

Results from the EBD questionnaires elucidated that caregivers are often overwhelmed and underprepared for the care that is needed once the patient returns home. Staffs' perceptions align with this finding. When staff were asked how they felt about the following statement, "Patients will get the help that they need regarding their delirium after discharge from the hospital", only 7% of the respondents (4/61) strongly agreed and 18 percent agreed (10/61).

Patients often described feeling paranoid, afraid, embarrassed and anxious—feelings that persisted after leaving the hospital. After returning home, some patients

remained fearful, sad and confused for many reasons, including not fully understanding their hospital experience, what delirium is, and why they experienced delirium. Patients were frequently not prepared for these emotions, nor did they feel they had been given the tools or resources to cope with them. In follow-up medical appointments, they revealed delirium was rarely discussed. Fear of the delirium returning may affect a patient’s approach to follow-up care and treatment.

Factors improving the delirium care experiences

Through EBD, we also elicited positive themes related to the care experience around delirium, particularly on collaboration between staff and caregivers, care strategies, and design of the care environment.

Collaboration between staff and caregivers

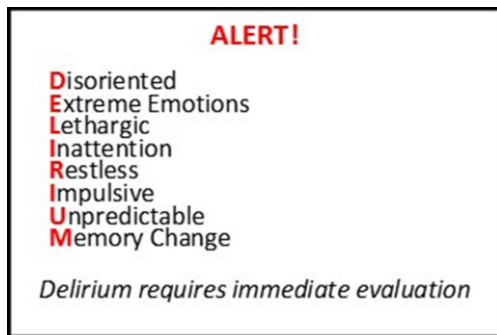
Staff reported positive experiences when there is a consistent presence of caregivers. Specifically, staff highlighted the value of the caregivers’ knowledge pertaining to the patient. Conversely, when caregivers are not present during a delirium episode, staff shared feelings of stress and frustration. Nursing staff, in particular, often incorporated strategies designed to provide emotional support for both patients and their caregivers. They emphasized the value of addressing upstream information needs—preparing patients for the possibility of delirium through pre-surgical delirium awareness and education.

*“Less emphasis on the CAM, more emphasis on interventions.”
(Clinical nurse leader)*

Care strategies

Patients mentioned how they appreciated human touch as a way to mitigate their fears and concerns when experiencing delirium. One patient described an instance when a nurse, “sat on the side of the bed and she hugged me for at least a minute ... and it was like one of those deals where ... it felt safe.” Touch helped to reorient patients emerging from a delirium episode and enabled patients to feel cared for and secure.

Figure 2. Delirium Symptom Checklist For Patients And Family Caregivers



Patients also described instances where staff challenged their delirious ideas and behavior. For example, “One nurse and I don’t know her name but I’m grateful for her. She put her hand on my arm and just looked at me in the face and said, ‘You’re not in Juneau. You’re in Seattle,’ and it was, like, boom! She made that connection with me that no one else had been making.”

Patients repeatedly mentioned that it was valuable to them when caregivers and staff did not agree with their delirious beliefs but instead gently challenged these thoughts as a means to reorient them.

Care environment

Nurses and caregivers shared specific strategies to help manage patients with delirium such as carefully adjusting the patients’ lighting to align with their circadian rhythm and creating familiar surroundings. One caregiver described how recognizable settings were essential to dealing with the delirium episode.

“When he got home into the familiar surroundings that really kind of pulled him out of it.”

Patients and caregivers also described the hospital environment as challenging, noisy, and disruptive—factors that may have contributed to and prolonged the delirium. As one caregiver suggested:

“The noisiness in the room and lights being real bright. Sometimes that’s aggravating...sometimes try dimming the lights if that makes things calmer.”

Co-Design in Delirium Care

The results of the EBD study were used in planning the co-design process and were shared with the co-design participants. In particular, the participants validated the EBD results and made several key determinations: (a) Medical personnel can have a difficult time identifying behavioral changes in hospitalized patients that may be associated with delirium; (b) Staff need to involve the patient’s family members and/or significant persons who know the patient best in identifying delirium risk factors and symptoms before entering the hospital; (c) The person who knows the patient best may not necessarily be a family member; (d) Once in the hospital, caregivers need to be invited to help staff detect behavioral changes in a patient to facilitate early action; (e) Delirium’s effects can be long-lasting and distressing, and therefore improvements should consider long-term effects.

In the co-design sessions, participants identified novel approaches to formalizing the caregiver role by incorporating this person as a care team member and creating new caregiver-centered toolkits. Participants developed two strategies to support caregivers: (1) a succinct patient card that provides a checklist of delirium systems and suggested actions for caregivers (Figure 2);

Figure 3. Delirium Symptom Tracking Board with Suggested Language for Communicating with Patients and Family Caregivers

Care Companion Name: _____ Mobile # _____

Delirium Questions:	Day 1 Baseline Date_____	Day 2	Day 3	Day 4	Day 5
Have you noticed sudden changes in your loved one's thinking or concentration such as being less focused or appearing confused or disoriented?	●				
Is your loved one rambling, disorganized, or not making sense?	●				
Is your loved one extremely drowsy or tired during the day?	●				
Is your loved one impulsive, yelling out, or acting aggressively?	●				
Does your loved one seem to hear or see things that aren't there?	●				
Comments:					

Green = No **Yellow** = Maybe, Not sure **Red** = Not normal, worse

and (2) a Delirium Symptom Tracking Board that caregivers update daily to provide their unique perspective on the patient's cognitive state (Figure 3).

Creation of these tools also underscored the language divide that can occur between deliverers of healthcare and patients and caregivers. Both patients and caregivers involved in the co-design work challenged how delirium was being described, expressed a need for greater clarity without jargon and requested staff not minimize the serious and even residual impact delirium can have. It required multiple prototype iterations to find an acceptable balance between the customers' communication needs and accurate use of clinical terminology.

Overall, the co-design sessions led to a breaking of assumptions around delirium, a focus on the caregiver role, empowerment of participants to help shape the language and instructions around delirium, and increased focus on post-hospital support after a delirium experience. Implementation of the results of the co-design process is now ongoing.

Discussion

This article details a comprehensive approach toward understanding and developing strategies for improving the delirium experience in hospitals. The emotional impact of delirium is presented from three key stakeholders'

perspectives involved in episodes of delirium. Our mixed-methods, experience-based design approach validated perceptions of gaps and challenges at key touch points, such as how patients cope with a delirium experience after leaving the hospital. Our hope is that by enhancing understanding of the patient and caregiver role during episodes of delirium we can promote greater support to increase caregiver involvement in the hospital.

Important concerns affecting the care experience for patients undergoing delirium include preparation for the possibility of delirium, education in both identifying and understanding delirium, and the lasting impact of a delirium episode. The results stress the importance of the caregiver in delirium detection and management, and the need for patient and caregiver support after a delirium episode. Through analysis of conversations with study participants, it was determined that caregivers: (1) often serve as early detectors of delirium; (2) are invaluable for helping patients re-orient during episodes of delirium; (3) often lack adequate preparation and training to be actively involved in delirium detection and response; (4) may be absent at critical times; (5) can create challenges to the delirium management and response; and (6) are frequently discussed as the person who best understands the patients' baseline cognitive state and behavior.

The emotion words used for the EBD questionnaire have been validated previously. However, the literature on the application of the full structured experience-based co-

design approach on diverse populations remains relatively limited.^{27, 29} The methodology has been endorsed by the National Health Service in the UK, and has been deployed in the US, Canada, New Zealand, Australia, and multiple nations in Europe.^{27, 30} Recently, researchers reported on the use of EBD to aid co-design for pancreatic cancer patients, spanning the entire disease process from diagnosis to end of life care.³⁰ Under the EBD approach, we uncovered and refuted a series of underlying assumptions about the care experience for pancreatic cancer patients. In addition, other authors have reported on the use of EBD interviews and focus groups for co-design, though without the structured and semi-quantitative EBD questionnaires.²⁷

Limitations

As with any qualitative study, our findings might not be fully representative of the populations under consideration. Despite making considerable effort to sample for a representative patient population, it is possible that our participants differ from other patients in terms of self-efficacy or their organization with managing their care. Additionally, the number of patients and caregivers interviewed was not as robust as the researchers would have liked. Patients and caregivers were reluctant to discuss their experiences; however, the sample size for questionnaire completion was significantly higher. Thus, through use of multiple methods of data capture and by exploring the perspectives of staff, patients, and caregivers, we were able to develop a comprehensive perspective on the delirium experience.

Conclusions

Our study provides new insights regarding the care experience for patients undergoing delirium episodes, and their caregivers (including family members and other companions). A key finding was the critical role of caregivers, who often serve as early detectors of delirium signs and symptoms. They are frequently discussed as the person who best understands the patients' baseline cognitive state and behavior, with an important assumption challenged that this is always a family member. Moreover, patients and staff described caregivers as invaluable for helping patients re-orient during lucid moments of a delirium episode. This knowledge reinforces that care processes must be redesigned to include caregivers or improved detection of early delirium cannot be expected. In addition, support should continue beyond the delirium episode, as the effects on both patients and family members can be long lasting.

This project also reinforced that words really matter. What we are saying is not always what patients or caregivers are hearing, or the implications are not being grasped as we assume. Many patients and families reported that delirium was never discussed, explained or even mentioned, which

could mean they did not recall the conversations, or our medical jargon did not result in a shared understanding. Our Delirium Symptom Tracking Board provided language to aid communication with caregivers. An additional suggestion is to apply teach-back or other method of verifying understanding when explaining delirium to patients and families. In summary, this project provides an example of a comprehensive approach to understanding the care experience to better enable patient and caregiver involvement in care redesign.

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Table 1. Delirium Experience-Based Design Assumptions Table

Category	Assumption	Learning	Quote
Preparing for possibility of delirium			
	Delirium will not happen to me.	Delirium can happen to anyone-it is a medical emergency.	<ul style="list-style-type: none"> ▪ “I was told by the doctors before my operation that it was likely to happen, and in my mind I said no, it’s not going to happen to me. I don’t do things like that.” • “I was not informed before the surgery of the possibility of delirium happening. It was very upsetting to me.” • “The word delirium wasn’t mentioned. It was more like things are going to be foggy, kind of hazy; you might not recognize faces, you know, when you first open your eyes, but it will pass.” • “It was an experience that I was not expecting.”
	Patients and caregivers know what delirium is.	Oftentimes, patients and caregivers do not know what delirium is until it occurs; and even then, it may still not be well understood.	<ul style="list-style-type: none"> ▪ “What kind of frustrated my caregivers was that they had no idea what delirium was.” ▪ “Before my heart surgery the Dr. told me I might experience delirium. But I really didn't know what that meant.” ▪ “I feel as if I still do not have a full understanding of the delirium my husband had.” ▪ “I picked up materials and anything that I didn’t understand when I went to my quarters at night, I was right on the Internet.” ▪ “They just told me that it was very possible that I would experience delirium, and I really didn’t know what delirium was.” ▪ “Offers of help to caregivers (to understand the delirium situation) would have helped me at that time.” ▪ “When the PA said, "I heard you were having hallucinations" that was all that was said! It should have been explained to me! Also, I should have been informed of the possibility.”
Identifying delirium			
	Only medical staff can identify delirium.	Medical personnel can have a difficult time identifying behavioral changes in hospitalized patients that may be associated with delirium. Caregivers are needed to collaborate and help staff detect behavioral changes in a patient.	<ul style="list-style-type: none"> ▪ “[My son] told me later he went to the nurses’ station and said, ‘Something’s wrong with him; he’s not acting right.’” ▪ “I think you would have a major job on your hands if you didn’t have a very good caregiver...The caregiver is a very important person.” ▪ “My husband was keeping notes and he and my mom would talk daily about what they noticed, you know, exchanging notes so they could talk to the doctors about it.” ▪ “The family keeps your mind where it belongs because the nurses aren’t part of your family. They’re strangers. They become part of the delirium; they’re the enemy.” ▪ “You want the patient and the family member to feel that they are learning too that the doctor isn’t the ultimate; that you can work with them and get information correct.”
	Family members know patient’s baseline cognitive state best.	People other than family members may know patient’s cognitive state best.	
Understanding delirium			
	Delirium varies in intensity and severity.	Delirium’s effects are often distressing and at times, terrifying for patients and caregivers.	<ul style="list-style-type: none"> ▪ “I actually thought they had moved me down to the morgue. That night I called my husband at 2:30 am was when I figured out how to commit suicide with the IVs.” ▪ “I wondered if he would come back to ‘normal’.” ▪ “A very scary situation...!! I thought I was being held hostage by the Russians. Locked in an attic etc. When my daughter came (I love her dearly, beyond words) I guess I was most ugly toward her-thinking she was one of "those" people keeping me hostage.”







Table 1. Delirium Experience-Based Design Assumptions Table (cont'd.)

	Written materials are sufficient education for caregivers.	Caregivers often reported feeling left in the dark and wanted to have more conversations with staff.	<ul style="list-style-type: none"> ▪ “It just would have been helpful if I would have had somebody take me aside, sit in a room, kind of go over it with me away from my husband because I was with him all the time...I was always asking questions and everybody was busy.” ▪ “I was given the pamphlet when he was in the ICU, so they gave it to me early on but not as early as I would have liked to have had it. I think they gave it to me after he had some of the symptoms.” ▪ “You’re so stressed out you just put the pamphlet aside, so if there had been the verbal conversation and sitting down that would have been more helpful.” ▪ “Information on delirium experience needs to be told just before the person leaves the hospital. (More than just a pamphlet).”
	We already give patients and families information on delirium.	Patients and caregivers need to receive multiple methods of education.	<ul style="list-style-type: none"> ▪ “I think if you had some kind of educational film that you could share with somebody going through this.” ▪ “The packet was really interesting for me to read it and find out that alcohol isn’t the only reason that causes [delirium].” ▪ “It would have been much more helpful to have somebody verbally sit down rather than just handing me a pamphlet.”
Lasting effects of delirium			
	Hospital discharge is positive for caregivers.	Caregivers often feel unprepared to assume responsibility to care for patients after delirium.	<ul style="list-style-type: none"> ▪ “There wasn’t any support after discharge.” ▪ “It would have really helped if there has been follow-up calls within a week after we were home. Really need health care support after leaving the hospital.” ▪ “I over estimated my ability to give effective care to my wife when she returned home.” ▪ “No one followed up.”
	Hospital acquired delirium is a temporary condition.		<ul style="list-style-type: none"> ▪ “That experience was so bad for me that I didn’t want to take any more painkillers. I was afraid I’d start taking them again...that it would start that delirium again.” ▪ “For about three months, I don’t remember anything or just a few things that were really very bothersome and I can’t even put those in place as to when they happened.” ▪ “This was overwhelming experience that took a long, long time to put in some kind of perspective.” ▪ “And I’m still going through that, depression.” ▪ “And I even like called the 24-hour line thinking that something’s wrong. You know, because I’ll wake up and I’ll lay there awake, my eyes open but I still don’t know if I’m in a dream or what.” ▪ “There was like 60 days missing out of my life, and I kept trying to reconstruct those 60 days.”

Appendix 1. Family Caregiver Experience with Delirium EBD Questionnaire

		Thank you for TRANSFORMING HEALTHCARE with us. By completing this questionnaire-- YOU are helping us improve everyone's experience at Virginia Mason.								
<u>CAREGIVERS: Please Tell Us About Your Family Member's Hospital Experience With Delirium</u>										
How were you feeling when the delirium episode occurred?		Circle ONE word that BEST describes your feeling	Angry	Hopeful	Okay	Afraid	Safe	Hopeless	Compassion	<u>Comments:</u>
How do you feel about the conversations you had with staff regarding treatment approaches?		Circle ONE word that BEST describes your feeling	Satisfied	Valued	Frustrated	Okay	Secure	Angry	Ignored	<u>Comments:</u>
How do you feel about how you were kept informed about your loved one's delirium experience?		Circle ONE word that BEST describes your feeling	Okay	Ignored	Frustrated	Pleased	Angry	Secure	Satisfied	<u>Comments:</u>
After the episode, how do feel about the way delirium was explained to you?		Circle ONE word that BEST describes your feeling	Pleased	Angry	Grateful	Frustrated	Safe	Okay	Afraid	<u>Comments:</u>
How do you feel about the way the healthcare team provided support after your loved one was home?		Circle ONE word that BEST describes your feeling	Hopeless	Ignored	Great	Depressed	Okay	Satisfied	Secure	<u>Comments:</u>

Appendix 2. Patient Experience with Delirium EBD Questionnaire

		Thank you for TRANSFORMING HEALTHCARE with us. By completing this questionnaire-- YOU are helping us improve everyone's experience at Virginia Mason.								
<u>PATIENTS:</u> Please Tell Us About Your Hospital Experience With Delirium										
How do you feel about the way delirium was discussed with you <i>before</i> the episode occurred?		Circle ONE word that BEST describes your feeling	Angry	Pleased	Okay	Frustrated	Satisfied	Ignored	Great	Comments:
How do you feel about the staff's approach to treating your delirium?		Circle ONE word that BEST describes your feeling	Satisfied	Pleased	Angry	Okay	Grateful	Sad	Frustrated	Comments:
After the episode, how do you feel about how the delirium was explained to you?		Circle ONE word that BEST describes your feeling	Okay	Frustrated	Sad	Secure	Angry	Pleased	Valued	Comments:
How do you feel about how you were supported after your hospital stay at home?		Circle ONE word that BEST describes your feeling	Pleased	Sad	Satisfied	Ignored	Great	Okay	Afraid	Comments:
How do you feel about your memories of the delirium episode?		Circle ONE word that BEST describes your feeling	Guilty	Afraid	Safe	Depressed	Okay	Secure	Satisfied	Comments: